



A-LiNK Connections Parent Volunteer Leader Description

Pediatric Autoimmune Hepatitis and Primary Sclerosing Cholangitis (PSC) represent a spectrum of Autoimmune Liver Disease (AILD), which present unique treatment challenges and can be associated with Inflammatory Bowel Disease (IBD). A-LiNK (Autoimmune Liver disease Network for Kids) is a network of pediatric centers throughout the nation that engage patients, families, providers, and other stakeholders as partners to improve outcomes in AILD. A-LiNK strives to facilitate productive, mutually respectful relationships and a shared understanding of key patient-centered outcomes.

As parents and guardians of children with AILD, the A-LiNK Connections Parent Community is committed to enhancing the quality of life for the young people and their families who live with AILD. In partnership with [ImproveCareNow](#) (a Learning Network focused on improving the lives of kids with IBD) and other pediatric liver care center teams, the A-LiNK Connections Parent Community empowers patients with AILD and their families to thrive in their lives by improving the quality and outcomes of their care.

Position Description:

The A-LiNK Connections Parent Volunteer Leader is an active member of the A-LiNK leadership team and serves as a liaison to the parents and medical care providers at their child's liver care center.

Time commitment: 4-5 hours, per month

Term: At least one year

Key Responsibilities:

- Understand the structure and goals of the A-LiNK Quality Improvement initiatives and help provide guidance in achieving these goals.
 - Provide feedback, advice, and patient/parent perspective on action period calls (once a month)
 - Attend and actively participate in leader meetings (once a month)
 - Read and respond to A-LiNK project email communications
 - Assist in the planning of content for the community conference (twice a year)
 - Make recommendations to for future content
 - Serve as a parent leader at your child's liver care center
 - Assist in the development of procedures, materials, and guidance for patients, parents, and leadership that will facilitate integration of patients and parents into the quality improvement work as participating members on behalf of their care centers
 - Solicit feedback from other parent leaders as resources are developed
 - Regularly share updates about network progress to parents at your child's liver care center
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Requirements, knowledge, skills, and abilities:

- ✓ Currently receives care from, or is the parent, guardian, or family member of a current patient at an A-LiNK care center
 - ✓ Prior experience working with their care center team
 - ✓ Has a general working knowledge of (or is willing to learn about) the A-LiNK strategy and goals
 - ✓ Understands (or is willing to learn about) basic quality improvement concepts
 - ✓ Able to identify key points, summarize them, and communicate to A-LiNK Connections leadership
 - ✓ Willing to agree to all relevant privacy agreements
 - ✓ Able to regularly attend learning lab meetings
 - ✓ Communicative
 - ✓ Patient and empathetic
 - ✓ Willing to learn
 - ✓ *Additional experience (recommended, not required):*
 - *Existing relationships with ICN staff*
 - *Working knowledge of the Learning Network organizational structure*
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If you are interested in becoming an A-LiNK Parent Leader for your Care Center please email the following information to lauren.grooms@cchmc.org

Subject Line: A-LiNK Parent Leader

First and Last Name:

Phone #:

Best way to get in touch:

Physician/Clinician who referred you to A-LiNK:

Care Center: